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ABSTRACT

This report uses a question and answer format to describe Project Innovative Parenting (P.I.P), a model project to provide assistance to parents with physical disabilities. The program offers such parents assistance in locating appropriate assistive technology, help in finding educational programs to teach and enhance parenting techniques, reinforcement of parenting skills already learned, and assistance with the linkage between parents and pertinent community services. Among questions addressed are the following: (1) What kind of parent does P.I.P. serve?; (2) How should this type of program be staffed?; (3) How did people learn about P.I.P. and what the program offered?; (4) How did P.I.P. establish positive relationships with community agencies?; (5) What happens after an interested parent contacts the program?; (6) What kind of issues might I expect to encounter while working with parents with special needs?; (7) Where did P.I.P. find recourses?; (8) What is assistive technology, and what kinds of technology might be helpful to a parent with a disability?; (9) Did P.I.P. buy assistive devices for parents? and (10) Did you get feedback from parents about the program and its effectiveness for them?. Brochures, forms, a family needs scale, an independent living assessment measure, an individual habilitation plan form, and handouts for parents are appended. (DB)

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Project Innovative Parenting

A Model For Serving Parents With Physical Disabilities

Lansing, Michigan
1993

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Project Innovative Parenting

Model

a project of

Michigan Developmental Disabilities Council

and

Physically Impaired Association of Michigan

December 1993

For more information contact:

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Limited number of copies available for $5.00 shipping & handling.

Preface

As so often with good things, positive results come from the vision, the commitment and the efforts of a number of people. So it has been with Project Innovative Parenting.

The seed was planted initially when one member of the Developmental Disabilities Council shared her vision of a project to benefit developmentally disabled parents with physical problems.

Caring persons in Michigan state government took it to the "proposal" stage, and followed through in assisting staff at the Physically Impaired Association of Michigan as they moved to formulate their procedures. In this regard we need to thank especially Carol Christensen, Grants Manager, Developmental Disabilities Council, and Nancy Stillson of the Michigan Department of Mental Health. Later, Dr. John Seeley of F.E.R.A. was to add his support and encouragement to the process.

The PAM Assistance Centre, P.I.A.M.'s resource center for low or "light" technology, was uniquely suited to implement a project such as P.I.P. As a result of this project, the PAM Centre has expanded its resources to include numerous devices to help parents with the care of young children — information which will be available to special populations on an ongoing basis.

Ellen Weaver, P.I.P.'s Project Coordinator, provided excellent leadership by establishing meaningful relationships with our mentors, the parents involved, and in some cases, even the children. Holly Brock, Leslie Lacy, and Barbara Abrams contributed to the overall project, each with her own talents. We are all most appreciative of the fact that the parents whom we have been privileged to know are facing their challenges with courage and, hopefully, truly benefiting from their contacts with us.

Arselia S. Ensign, Ph.D.
P.I.P. Project Director
Physically Impaired
Association of Michigan

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Project Innovative Parenting

What Is It?

Project Innovative Parenting (P.I.P.) is a model project supported by a grant from the Michigan Department of Mental Health as the Administering Agency for the Michigan State Planning Council for Developmental Disabilities awarded pursuant to P.L. 100-145, as amended, the Developmental Disabilities Assistance and Bill of Rights Act.

The purpose of P.I.P. is to empower handicappers with the appropriate skills and resources to achieve their maximum potential as parents. The program offers parents assistance in locating appropriate assistive technology, help in finding educational programs to teach and enhance parenting techniques, reinforces parenting skills already learned, and assists with the linkage between parents and pertinent community services.

What kind of parents does P.I.P. serve?

Handicapper parents of children under age 6, handicappers expecting a baby, or those thinking about starting a family who are experiencing appreciable physical limitations (not mentally impaired) may benefit from this program. For the purpose of this grant funded by the Michigan Developmental Disabilities Council, we worked with individuals meeting criteria specified in the federal definition of developmentally disabled (P.L. 95-602). P.I.P. used the following:

> The developmentally disabled are persons with physical disabilities who are functioning within a normal range of intelligence. Their disability must have been manifested before the age of twenty-two and be likely to continue indefinitely. Parents are eligible for P.I.P. if their disability results in substantial functional limitations in three or more of the following areas: (a) self- care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, or (g) economic self-sufficiency.

However, we found that handicappers not meeting this criteria due to a less severe disability, onset of a disability after age twenty two, or only temporarily disabled could also greatly benefit from some of the services offered.

Biological, adoptive or foster mothers, fathers and/or grandparents could be eligible. Handicapping conditions of parents served through P.I.P. included cerebral palsy, hearing impairment, visual impairment, closed head injury, fibromyalgia, spinal cord injury and arm amputation.

How should this type of program be staffed? Are any special qualifications required?

Minimally, any staff members working directly with parents should themselves be parents. Optimally, any staff "parent" who also has a disability would be ideal. These qualifications would enable staff to relate more easily to clients and to be more empathetic to their needs and concerns.

P.I.P. was staffed as follows:

Project Director
Program Coordinator
Resource Coordinator
Secretary

Both the Program Coordinator and the Resource Coordinator had contact with clients. The Program Coordinator had education and experience as a registered nurse, a rehabilitation nurse and a rehabilitation counselor and successfully functioned as a parent with a physical disability. The Resource Coordinator had education and experience as a special education teacher and also functioned successfully as a parent with a visual impairment.

Feeling comfortable working with handicappers is essential.

How did people learn about P.I.P. and what the program offered?

To begin, a brochure and flier were designed. (See Appendix A.) The brochure, intended for professional use, contained information describing the purpose of P.I.P., eligibility requirements for program participants including the definition of developmentally disabled, and what the program had to offer parents. The flier was designed to give to potential program participants. It was the responsibility of interested individuals to contact P.I.P. to initiate program services.

Contacts were made and literature distributed within various community agencies such as: Michigan Department of Social Services, Public Health Department, Centers for Independent Living, Michigan Rehabilitation Services, Michigan Protection and Advocacy, Community Mental Health, Family Growth Center, LAP Respite Center, area Intermediate School Districts, and local hospitals, churches and service organizations. Mailings were followed by phone calls or personal contact. Sometimes a brief inservice was appropriate to inform professionals of the purpose of the program and what it had to offer handicapper parents.

How did PIP establish positive relationships with community agencies?

After the initial flyers were sent, follow-up was done with phone calls and personal contacts. At every professional meeting, PIP staff made a deliberate effort to speak with other professionals about the PIP program.

What happens after an interested parent contacts the program?

Once a parent decides to become involved in the program, arrangements are made for an initial home visit if possible. Sometimes distance makes travel to the home an impossibility. In such a case, a great deal of helpful information can still be obtained over the telephone. It is advisable for two staff members to be involved, at least in the first visit. Going into an unknown environment, it is safer to go as a team. Also, a team approach brings in variety, not only with personal experience, but also with professional experience. Casual dress is usually best so as not to appear intimidating to the family. It may even be necessary to sit on the floor.

Establishing rapport with clients is crucial and begins as soon as contact is made. Home visits offer an opportunity to build a relationship with personal interaction. It also enables staff to make an assessment of the parent's disability, strengths and weaknesses, environment, actual physical characteristics of the home, and how parent and child interact and respond to each other. A major key in establishing rapport is listening and respect. Reflect and rephrase what the parent is saying to be sure you understand what they have expressed.

If possible, arrange your first visit with parent(s) when the children are not home. It is much easier to concentrate and communicate with as few interruptions and distractions as possible. It is an especially good idea to talk with parents without children nearby if one of the concerns of the parent is the child's behavior . Even if it is not obvious, children are usually taking in the conversation of the adults, particularly if their name has been mentioned.

Did P.I.P. use any special forms?

At the beginning of the initial visit, it is necessary for the parent(s) to sign a Permission Form and Consumer Information Release (see Appendix B). This legally gives you permission to work with the parent(s). It also will allow you to discuss that client with other service agencies, which most often is necessary.

Other forms found in Appendix B can assist you in gathering helpful information from clients. However, more often they are tools that help initiate conversation with parents. They may help them to begin thinking about different areas of their lives where they are having difficulty or perhaps to establish priorities and plans for achieving them. Some of the forms are designed to be left with parents to be completed at a later time and on their own. Again, they are designed to provoke thought and self evaluation.

After every interaction with a parent, whether in person or on the telephone, it is a good idea to jot down a few notes about what was said or what happened during the visit (see Case Notes form in Appendix B). The written notes may be helpful at a later date. It also provides you with a specific place to write any special notations you may wish to make regarding the family.

After the initial home visit, what's next?

Sometimes, after a home visit, it appears that all a family really needs is literature, resource material or a simple piece of technology. This information can be mailed to them. A follow-up phone call indicates support to the family and offers the opportunity for any further questiions to be asked.

Attitude may be the largest barrier to successful parenting for handicappers. Education of professionals, agencies and the community is essential.

At times, crisis management is the only issue parents can address. Immediate intervention is often crucial. Families may have difficulty obtaining food, shelter, or might need help so utilities won't be turned off. Finances need to be resolved before parents can concentrate on "parenting skills".

Generally however, parents need more assistance in a variety of areas and in a more intensive manner. This is the time to begin writing an Individualized Habilitation Plan (see Appendix C). From your observations and the client's input, plans and strategies are initiated to accomplish the goals you establish together. It is important to remember that the goal of the program is to encourage parents to become independent, not dependent. They need to take care of as many of their own responsibilities as possible. At times you may need to intervene with a community agency, or make inquiries to insure that the parents will contact the proper resource and have a successful interaction with that agency. But the parent should be directly involved. From time to time the IHP may need revision. Again, it is a guide to encourage thinking and planning on the part of the parent(s).

How did P.I.P. establish positive relationships with community agencies?

Initially, P.I.P. brochures were mailed to various community agencies, for the purpose of linforming them and the professionals within those agencies about the new program in their community. As follow-up, P.I.P. staff made phone calls and/or personal contacts with individuals. At every professional meeting P.I.P. staff also made a determined effort to speak with other professionals about the program. P.I.P.'s involvement with families with special needs was often welcomed by other agencies involved with the family. Due to the uniqueness of the P.I.P. program, it allowed time to work with families on issues that perhaps another agency could not easily find time to do. Working together is essential and usually quite helpful.

What kinds of issues might I expect to encounter while working with parents with special needs?

For an individual with a disability, parenting skills and issues may need to be approached in a different and creative manner. These parents may run into obstacles that non-handicapper parents would not. Parenting with a disability is a relatively new trend and sometimes unique circumstances arise and must be addessed for the first time.

Attitude may be the largest barrier to successful parenting for handicappers. Education of professionals, agencies, and the community is essential.

Crisis intervention may be necessary, as problems with obtaining food, shelter, heat, and financing have to be resolved before parents can concentrate on "parenting skills."

Private and public service agencies may need to be educated by inservices, written information, and dialogue as to the needs of a handicapper parent. In some cases, an expectant mother with a disability may need to visit the hospital where she will deliver and see if the facilities are accessible according to her needs. Staff and parents should discuss issues of labor and delivery and potential difficulties that may arise due to a particular disability.

Frequently handicappers are not aware of community programs and services that are available to them. Providing them with pertinent information can often be the answer to what may seem like a large problem. At times it may be necessary to talk with case workers or other professionals involved to clarify or give and receive additional helpful information about the family. If you encounter a parent who is negative or has had a bad experience with an agency or individual in the past, encourage her or him to try again.

What are some other parenting issues I might expect to encounter in this type of program?

Sometimes persons with a disability are not certain about "normal" growth and development and are eager to find information that describes typical behaviors and skills that they might expect to find as their children grow and develop. This kind of information is available from a variety of sources. We stress that the guidelines are simply that - guidelines. They function as a reference, and the ages at which children reach these stages are quite variable.

Another concern that often arises is that of discipline. Children learn at an early age what their parents' weaknesses are and can take advantage. There are many theories as to how children should be disciplined, and we did not promote or recommend any particular one. We have collected articles and information on positive discipline and general behavior management techniques and shared these with parents from time to time. If a child appeared to demonstrate unusual or severe behavior problems, we found a resource in the community that professionally addresses such issues and referred the parents there.

Child safety is very important. Child-proofing the home should be discussed while the baby is still an infant. And as the child grows, different issues need to be considered and addressed. Provide the parents with information on child and home safety so they can have it for immediate reference.

In the P.I.P. program we supplied each family with a special P.I.P. notebook for them to keep at home. This offered them a specific place to keep relevent literature, information, names and phone numbers. Standard notebook contents initially given to parents included: charts and basic information on normal growth and development, tips on appropriate non-punitive child discipline, a poem or two, and P.I.P. staff names and phone numbers (Appendix D). From there on, notebooks became specialized according to individual needs. Whatever is relevent to a parent's or child's particular needs can sometimes be addressed from books, articles or other resources. (A listing of available resources can be found in Appendix D. These resources are continually updated.) These types of things can be stored in the notebook so as not to be lost or accidentally thrown away.

Where did P.I.P find resources?

Many periodicals dealing with disability issues of parenting were constantly researched, computer information lines were scanned, field trips to various stores were frequently made, and a mentor group established for peer support, made many valuable suggestions.

What is assistive technology, and what kinds of technology might be helpful to a parent with a disability?

An assistive device is something that is used to enable a person to accomplish a task. Technology can be purchased, home-made or achieved by making an alteration to an existing product. This can range from elaborate and expensive adapted baby furniture to a simple Velcro diaper, or an adaptation to a baby bottle making it easier for mom or dad to hold while feeding baby. There are many items and techniques available that can make the task of parenting easier, or even possible at all. Some commercially available products, as well as ideas for simple adaptations, can be found in the PAM Repeater, "Parenting With A Disability", found in Appendix E.

The PAM Assistance Centre is a valuable resource serving as an information center on adaptive equipment. Services are free and available to anyone. For more information, see Appendix E.

A technique, minor adjustment or alteration to a product can sometimes be just as effective as a specialized piece of equipment. We like to share with parents some of the little things we ourselves have tried or that another parent has found to be successful and shared with us. Sharing ideas doesn't cost anything. Always demonstrate for the parent how an assistive device is supposed to be used, keeping safety of the parent and child in mind. Have the parents try using it while you are there so that necessary changes or adjustments can be made before they try using it when alone. Creative solutions for accomplishing a task should also be demonstrated, such as lifting a baby using only one arm, or transferring a baby from one place to another from a wheelchair.

Did P.I.P. buy assistive devices for parents?

The P.I.P. project was not designed to purchase adaptive equipment. However, on occasion we were able to buy a few small items that would enable a parent to accomplish a parenting task more easily. Once we put a down payment on a closed circuit TV (CCTV) magnification system for a family of four, all of whom were visually impaired. This enabled them to purchase the CCTV on a payment plan. This device was the solution to many of the problems facing the parents. On occasion we also gave parents books, as an educational tool or just a story book to read to their children.

Did you get feedback from parents about the program and its effectiveness for them?

At the end of the first year of the program an evaluation questionnaire was sent to all families that were actively involved at that time, or who had been served at one time by the program (see Appendix F). The responses received were positive.Their input assisted us in making changes in the program to better meet their needs.

APPENDIX A

P.I.P.

PROJECT INNOVATIVE PARENTING

If the answer is YES to these questions, maybe P.I.P. can help:

- ***Do you have a physical disability that you have had since you were young?***
- ***Do you have questions about having children?***
- ***Do you look after a child who is 6 years old or younger?***
- ***As a parent with a handicap, do you have trouble doing things you need to do?***

P.I.P. helps parents who have disabilities learn about:

- *normal infant and child development*
- *parent/child bonding*
- *physical management of young children*
- *discipline*
- *selection of appropriate toys*
- *finding special equipment for child care*

For more information about P.I.P. contact:

Project Innovative Parenting
PAM Assistance Centre
601 W. Maple
Lansing, MI 48906
(517) 371-5897 or 1-800-274-7426
Voice or TDD

The production of this brochure was supported by Grant #91245 from the Michigan Department of Mental Health as the Administering Agency for the Michigan State Planning for Council for Developmental Disabilities, awarded pursuant to P.L. 100-145, as amended, the Developmental Disabilities Assistance and Bill of Rights Act.

FORTY-EIGHT MONTHS (4 YRS)
HOPS IN PLACE • THROWS BALL OVER HEAD, CATCHES BALL BOUNCED TO HIM • COPIES CIRCLE • POINTS TO 6 BASIC COLORS • KNOWS OWN SEX, AGE, LAST NAME • BEGINS TO PLAY WITH OTHER CHILDREN • USES SENTENCES WITH CORRECT GRAMMAR, SUCH AS CAN I GO TO THE STORE? I WANT A BIG COOKIE • WASHES HANDS UNASSISTED
SIXTY MONTHS (5 YRS)
AGE ONE MONTH
AGE TWO MONTHS
AGE THREE MONTHS
AGE FOUR MONTHS
AGE SIX MONTHS
AGE NINE MONTHS
TWELVE MONTHS (1 YEAR)
FIFTEEN MONTHS
EIGHTEEN MONTHS
TWENTY-FOUR MONTHS (2 YRS)
THIRTY-SIX MONTHS (3 YRS)
from Crib to Kindergarten
A GUIDE TO YOUR CHILD'S DEVELOPMENT

BEST COPY AVAILABLE

This handy guide shows the normal signs of growth in a young child. Many children develop faster than this. Those who develop slower than this, however, may be "special children" who may have special needs **now.**

If you think your child may have special needs, get in touch with the special education director or the superintendent of you local schools. The schools want to know about all "special children," even those below school age. They may have programs available for preschool-age children with special needs. If not, they can help you find agencies in your community that do offer services to very young children.

REMEMBER: The earlier you recognize your child's special needs and seek help, the better the possibilities are for your child to lead as normal a life as possible.

MICHIGAN PROJECT FIND
1-800-252-0052

MICHIGAN STATE BOARD OF EDUCATION
MICHIGAN DEPARTMENT of EDUCATION
Special Education Services
P.O. Box 30008
Lansing, MI 48909

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PROJECT INNOVATIVE PARENTING

PAM Assistance Centre
601 W. Maple
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(517) 371-5897 • 1-800-274-7426

WHAT IS P.I.P.?

P.I.P. stands for **Project Innovative Parenting**. The purpose of P.I.P. is to empower developmentally disabled people with the appropriate skills and resources to achieve their maximum potential as parents.

WHY WAS P.I.P. DEVELOPED?

In light of recent social and medical changes, increasing numbers of people with physical disabilities are becoming parents. Adapting to the role of parenthood requires adjustment for all persons. However, adjusting to parenthood for some persons with physical disabilities requires additional accommodations. Accommodations not only refer to typical lifestyle changes, but also to environmental adaptations and assistive technology for making independent child care a possibility.

WHO IS DEVELOPMENTALLY DISABLED?

For the purpose of this project, the developmentally disabled are persons with physical disabilities who are functioning within a normal range of intelligence. Their disability must have been manifested before the age of twenty-two and be likely to continue indefinitely. Parents are eligible for P.I.P. if their disability results in substantial functional limitations in three or more of the following areas: (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, or (g) economic self-sufficiency.

WHO CAN BENEFIT FROM P.I.P.?

Parents of children under age 6, or prospective parents living in Ingham, Eaton or Clinton counties who are experiencing appreciable physical limitations may qualify. Biological, adoptive or foster mothers, fathers and/or grandparents of any age are eligible if they meet the requirements outlined in the federal definition of developmentally disabled (P.L. 95-602).

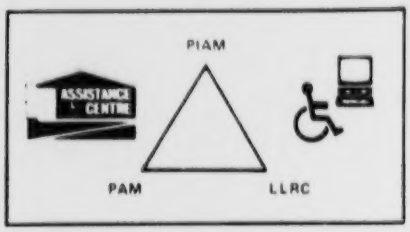
WHAT CAN P.I.P. OFFER PARENTS?

Through P.I.P. parents have the opportunity to benefit from: (1) peer support, (2) assistance in locating appropriate assistive devices, (3) educational programs to enhance parenting skills, and (4) linkage between parents and community services relevant to their individual needs.

APPENDIX B

Physically Impaired Association of Michigan
PAM Assistance Centre
Living and Learning Resource Centre

601 W. Maple Street
S. of MI School for Blind
Lansing, MI 48906



Information and Assistance
For Persons Who May Benefit
From an Assistive Device

Voice or TDD
517-371-5897
1-800-274-7426
FAX: 517-371-5898

Physically Impaired Association of Michigan
PAM ASSISTANCE CENTRE

PERMISSION FORM
Consumer Information Release

I agree to participate in Project Innovative Parenting.

Name_____

Address_____

_____

I hereby authorize the PAM Centre to give and receive medical, financial and social information for case planning and management and delivery of services.

_____

_____

_____

I am requesting your cooperation in this matter so that the PAM Centre may better assist me in innovative parenting.

_____
Date

_____
Client Signature

_____
PAM Staff Signature

_____
Title

The Pam Assistance Centre, a program of the Physically Impaired Association of Michigan, is funded in part as a State-Initiated Project of the Michigan Board of Education.

PARENT INFORMATION

DATE_____

NAME_____

ADDRESS_____

PHONE_____

BIRTHDATE_____ MOM _____DAD

DISABILITY_____ MOM _____DAD

CHILDREN_____ BIRTHDAY_____

_____ BIRTHDAY_____

_____ BIRTHDAY_____

_____ BIRTHDAY_____

ETHNIC BACKGROUND

_____ MOM _____ DAD

INCOME

_____$15,000 or less _____$25,000 to $50,000

_____$15,000 to 25,000 _____$50,000 +

_____SSI _____SSDI _____ADC _____WIC

Family Needs Scale

This scale is adapted from the Family Needs Scale and Family Resource Scale.
Carol M. Trivette, Carl J. Dunst, & Angela G. Deal

Name_____Date_____

This scale asks you to indicate if you have a need for any type of help or assistance in 41 different areas. Please circle the response that best describes how you feel about needing help in those areas.

To what extent do you feel the need for any of the following types of help or assistance?	DOES NOT APPLY	NOT AT ALL ADEQUATE	SELDOM ADEQUATE	SOMETIMES ADEQUATE	USUALLY ADEQUATE	ALWAYS ADEQUATE
Food for two meals a day	NA	1	2	3	4	5
Having time to cook healthy meals for my family	NA	1	2	3	4	5
House or apartment	NA	1	2	3	4	5
Budgeting money	NA	1	2	3	4	5
Enough clothes for my family	NA	1	2	3	4	5
Heat for my house or apartment	NA	1	2	3	4	5
Completing chores, repairs, home improvements	NA	1	2	3	4	5
Money to pay monthly bills	NA	1	2	3	4	5
Good job for myself or spouse / partner	NA	1	2	3	4	5

	DOES NOT APPLY	NOT AT ALL ADEQUATE	SELDOM ADEQUATE	SOMETIMES ADEQUATE	USUALLY ADEQUATE	ALWAYS ADEQUATE
Medical care for my family	NA	1	2	3	4	5
Having emergency health care	NA	1	2	3	4	5
Public assistance (SSI, AFDC, medicaid, etc.	NA	1	2	3	4	5
Dependable transportation (own car or provided by others	NA	1	2	3	4	5
Time to get enough sleep / rest	NA	1	2	3	4	5
Furniture for my home or apartment	NA	1	2	3	4	5
Time to be by myself	NA	1	2	3	4	5
Time for family to be together	NA	1	2	3	4	5
Dental care for my family	NA	1	2	3	4	5
Someone to talk to	NA	1	2	3	4	5
Getting in touch with people I need to talk to	NA	1	2	3	4	5
Time to socialize	NA	1	2	3	4	5
Take care of myself	A	1	2	3	4	5
Money to buy things for myself	NA	1	2	3	4	5
Money for family entertainment	NA	1	2	3	4	5
Money to save	NA	1	2	3	4	5
Time and money for travel / vacation	NA	1	2	3	4	5

HEALTH AND SAFETY CHECKLIST

	YES	NO	COMMENT
Emergency Precautions			
The home has a telephone always operating			
Emergency numbers are posted by the phone			
Is home wheelchair accessible?			
Fire Safety			
Windows and doors are accessible and easy to open for evacuation in case of fire			
Electric wires are in good condition (not frayed or exposed)			
Fireplace has a protective device to shield a child from fire			
Home has central heating or permanently installed space heaters (no portable space heaters will be used during respite care)			
Family has fire drill plan which they practice with all family members			
Fire extinguisher in the home (optional)			
Smoke alarm in the home (required)			
All flammable materials are securely out of reach of a child or disabled adult (matches, gasoline, etc.)			
Is there smoking in the house?			

	YES	NO	COMMENT
Safety and Accident Prevention			
Household poisons are well out of reach of a child			
All medicines are out of reach of a child, or locked in a cabinet			

HEALTH AND SAFETY CHECKLIST (ccn't)

All hazardous materials are securely out of reach of a child (tools, plastic bags, sharp objects, etc.)			
Firearms must be locked			
Hot water pipes, steam radiators, space heaters etc. are shielded to protect against burns			
Furnace, water heater, heating appliances, pipes, etc. are in safe condition and not accessible to children			
Stairs or other areas considered dangerous can be closed or blocked off			
Sanitation and Food Handling			
Refrigerator is used for all perishable foods and keeps steady temperature below 45 degrees			
Outside doors and windows are screened			
Garbage cans are tightly covered			
Garbage and refuse containers are emptied regularly			

	YES	NO	COMMENT
Are there pets in the home?			
Pets are not allowed on food preparation table or counters			
<u>Water and Sewage</u>			
Each sink and lavatory has safe drinking water			
Water supply is from public system			
Well water has been tested			

Date_____Results_____

INDEPENDENT LIVING ASSESSMENT

Client Name_____Date_____

Address_____Staff_____

_____

Phone_____

1. Educational Interests

   Do you want to continue your education? ___Yes ___No

   Comments_____

   _____

   _____

2. Vocational (Employment) Interest

   Do you have an open case with Michigan Rehabilitation Services (MRS) ? ___Yes ___No

   Who is your counselor/case worker?_____

   Would you like to be referred to MRS? ___Yes ___No

   Have you ever had a MRS counselor? ___Yes ___No

   Skills/Interests (Please list)_____

   _____

   _____

3. What services have you or are you receiving from the Department of Social Services? (please list)

_____

_____

4. Independent Living History

Are you living on your own? ____Yes ____No

Have you ever lived on your own before?

With a disability ____Yes ____No

Before your disability ____Yes ____No

Comments_____

_____

Have you ever or do you use personal care attendance in your home? ____Yes ____No

Did/do you interview and hire the PCA's? ____Y es ____No

Did/do you pay your PCA's yourself? ____Y es ____No

Have you ever written a PCA job description? ____Yes ____No

Do you drive? ____Yes ____No

Did you ever drive? ____Yes ____No

Do you currently have a driver's license? ____Y es ____No

How often is help needed?

____periodic assistance - weekly but not daily
____daily assistance - less than 4 hours per day
____daily assistance - 5 hours per day or more
____live-in PCA or group residence
____not known - no experience

Personal Care Assistance

	No Help	Some Help	Help Needed
Transferring	_____	_____	_____
Bathing	_____	_____	_____
Dressing	_____	_____	_____
Personal hygiene	_____	_____	_____
Changing position in bed	_____	_____	_____
Toileting (general)	_____	_____	_____
Catheter care	_____	_____	_____
Ostomy care	_____	_____	_____
Bowel program	_____	_____	_____
Eating	_____	_____	_____
Food preparation	_____	_____	_____
Housekeeping	_____	_____	_____
Laundry	_____	_____	_____
Banking	_____	_____	_____
Shopping	_____	_____	_____
Ventilator	_____	_____	_____
Reading	_____	_____	_____
Writing	_____	_____	_____
Transportation	_____	_____	_____
Other - specify	_____	_____	_____

Comments_____

_____

_____

What do you pay for PCA? $_____

How much can you afford to pay? $_____

5. Physical/Mental Health Status

Do you have a physician? ___Yes ___No

When was your last physical examination? _____

Are you currently taking any prescription medication? ____Yes ____No

Describe_____

Have you been in the hospital recently? ____Yes ____No

For what?_____

Do you have any physical/mental health concerns? ____Yes ____No

Skin_____

_____

Urinary tract_____

_____

Stamina_____

_____

Dietary_____

_____

Depression_____

_____

Anxiety_____

_____

Paranoia_____

_____

Fear_____

_____

Anger_____

_____

Other (seizure, pain, fatigue)_____

_____

Has your physical/mental health changed in the last year?

____Yes ____No

If yes, how?_____

_____

_____

_____

Are you currently in psychotherapy? ____Yes ____No

Describe_____

_____

Have your mental health concerns been diagnosed? ____Yes ____No

Other areas of concern

Comments_____

_____

6. Personal Relationships

How does your disability affect your relationship with others?

In social activities_____

_____

_____

Your self perception_____

_____

_____

How others perceive you_____

_____

_____

7. Sexuality

How does your disability affect your sexuality?

Your self image_____

_____

_____

Your sexual activity_____

_____

_____

Would you like to talk with a sex educator/therapist? ____Yes ____No

Comments_____

_____

_____

8. Planning your own activities

Do you plan your own day? ____Yes ____No

Do you schedule social activities?_____

_____

Do you ask friends/family to attend events/social activities with you?

_____

_____

_____

9. Making choices

Do you make your own decisions regarding:

Your health_____

Your social life_____

Your personal life_____

Who do you talk with when you need to discuss making decisions/needing support?

_____

_____

10. Communication

Do you think that you express yourself as well as you would like to?

____Yes ____No

Comments_____

_____

_____

Would you like to change your communication style? ____Yes ____No

How?_____

_____

_____

11. Budgeting

Do you manage your own finances? ___Yes ___No

Do you follow a budget? ___Yes ___No

Do you think you are managing your finances effectively?

___Yes ___No

Comments_____

_____

_____

12. Self Determination/Motivation

What are <u>your</u> responsibilities in working towards independence?

_____

_____

_____

_____

_____

_____

_____

_____

_____

This part of the scale asks you to do two things: (A) begin by listing up to 10 needs or activities that are of concern to you. We call those things projects because they require our time and energy. Projects include things like finding a job, paying the bills, finishing school, playing with our children, going on vacation, teaching our children how to eat, and so on.

Which persons or groups listed to the right would you go to for help with any of these projects? PROJECTS	My self	Spouse or Partner	My Children	My Parents	Spouse or Partner's Parents	Sister/ Brother	Spouse or Partner's sis./bro.	Other Relatives
1.								
2.								
3.								
4.								
5.								
6.								
7.								
8.								
9.								
10.								

(B) After you have listed up to 10 projects please indicate which persons or groups you go to if you need help with any of the projects. Indicate who would provide you help by checking the appropriate box for the person or group that you would ask.

	Friends	Neighbors	Church Members/ Minister	Co-workers	Babysitter Daycare or School	Private Therapist for Child	Child/ Family Doctors	Early Childhood Interven. Program	Health Dept.	Social Services Dept.	Other Agencies
1.											
2.											
3.											
4.											
5.											
6.											
7.											
8.											
9.											
10.											

CASE NOTES **NAME**_____

DATE_____

APPENDIX C

INDIVIDUAL HABILITATION PLAN

Client Name_____ Date_____

File #_____ Worker_____

Review_____ _____

Area of Need

L = Long term N = Not applicable S = Short term O = Obtained

1. Housing ____
2. Independent Living Skills ____
3. Transportation/Mobility ____
4. Emotional Stability ____
5. Social ____
6. Medical Stability ____
7. Attendant Care ____
8. Pain Management ____
9. Equipment ____
10. Financial ____
11. Employment ____
12. Judgment, Decision Making/Motivation ____
13. Other ____

Area #1 - Housing

Goal

Objective

Intervention

Target Date

Area #2 - Independent Living Skills

Goal

Objective

Intervention

Target Date

Area #3 - Transportation/Mobility

Goal

Objective

Intervention

Target Date

Area #4 - Emotional Stability

Goal

Objective

Intervention

Target Date

Area #5 - Social

Goal

Objective

Intervention

Target Date

Area #6 - Medical Stability

Goal

Objective

Intervention

Target Date

Area #7 - Attendant Care

Goal

Objective

Intervention

Target Date

Area #8 - Pain Management

Goal

Objective

Intervention

Target Date

Area #9 - Equipment

Goal

Objective

Intervention

Target Date

Area #10 - Financial

Goal

Objective

Intervention

Target Date

Area #11 - Employment

Goal

Objective

Intervention

Target Date

Area #12 - Judgment, Decision Making/Motivation

Goal

Objective

Intervention

Target Date

Area #13 - Other

_____

_____

_____

_____

Goal

_____

Objective

_____

Intervention

_____

Target Date

_____

I acknowledge that the preceded goals and objectives have been established jointly by myself and my counselor, and the responsibility of achieving these goals is mine. I understand that it is my counselor's responsibility to provide guidance and support in achieving these goals, as well as direct assistance when it is jointly agreed upon as necessary

_____ _____

Client Signature Date

_____ _____

Worker's Signature Date

APPENDIX D

HOW TO REALLY LOVE A CHILD

Be there. Say yes as often as possible. Let them bang on pots and pans. If they're crabby put them in water. If they're unlovable, love yourself. Realize how important it is to be a child. Go to a movie theatre in your pajamas. Read books out loud with joy. Invent pleasures together. Remember how really small they are. Giggle a lot. Surprise them. Say no when necessary. Teach feelings. Heal your own inner child. Learn about parenting. Hug trees together. Make loving safe. Bake a cake and eat it with no hands. Go find elephants and kiss them. Plan to build a rocketship. Imagine yourself magic. Make lots of forts with blankets. Let your angel fly. Reveal your own dreams. Search out the positive. Keep the gleam in your eye. Mail letters to God. Encourage silly. Plant licoruce in your garden. Open up. Stop yelling. Express your love a lot. Speak kindly. Paint their tennis shoes. Handle with caring.

CHILDREN ARE MIRACULOUS !

SALK 90

CHILDREN
Learn What They Live

If a child lives with criticism,
he learns to condemn.

If a child lives with hostility,
he learns to fight.

If a child lives with ridicule,
he learns to be shy.

If a child lives with shame,
he learns to feel guilty.

If a child lives with tolerance,
he learns to be patient.

If a child lives with encouragement,
he learns confidence.

If a child lives with praise,
he learns to appreciate.

If a child lives with fairness,
he learns justice.

If a child lives with security,
he learns to have faith.

If a child lives with approval,
he learns to like himself.

If a child lives with acceptance and
friendship, he learns to find love
in the world.

Abbey Press / Meinrad, IN

STEPS IN POSITIVE DISCIPLINE

1. Work with the child to set a few basic rules.

2. Decide together what consequences will result from breaking the rules. (Time-out, loss of privilages, making repairs or amends.)

3. Ignore minor irritating behavior.

4. Praise and reward positive behavior. Be specific with praise. Don't use food as a reward.

5. Use consequences consistently and calmly when rules are broken.

RESOURCE LISTING

Lansing Community Resources

1. Wexford Pre-Primary Program
2. Capital Area Resource Guide
3. Community Resource Directory
4. Tri County Office on Aging
5. Deaf Options
6. LAP Respite Center
7. Region 13 Parenting Class
8. Special Education
   Protection & Advocacy Services and Publications
9. Resource Directory
   Handicapper Organizations
10. SSI SSDI ADCF
11. Michigan League for Human Services
12. Free Clinics

13. Caring for Children

14. Family Growth Center

15. Mary Free Bed

16. Skip-R Program Sinai Kids

Articles

1. "One Mothers Experience"

2. "Baby Basic"

3. "Sling Shift"

4. "You Can Find the Right Pre School"

5. "Ages and Stages"

6. "Effects of TBI on Parenting"

7. "Quad Dad Proves Fitness for Parenthood"

8. "Should a Daughter Help with Dad's Care"

9. "Who'll Teach Michael to Play Baseball"

10. "What To Do When Kids Cling"

11. "Loving Your Children-Getting the Have Message Across"

12. "Child Custody"

13. "One Handed Resources"

14. "How You Can Help Your Kids Adjust"

15. "A Mother's Courage"

16. "Single Parents"

17. "Spinal Cord Injured Women, Pregnancy"

18. "Child Care"
Arthritis Handbook

19. "You and Me and Baby Makes 3, or 4 or 5"

20. "Women With Disabilities Talk About Life"

21. "How Do You Know You're Ready?"

22. "Should I Have a Baby?"

23. "Sibling Rivalry"

24. "Children of Handicapped Parents"

25. Mainstream — September 1992

26. "I'm Having a Baby"

27. "The Challenge of Pregnancy"

28. "Parenting Despite Disabilities"

29. "Parenting: A Disabled Woman's Greatest Challenge"

30. "Mothers With Impaired Mobility Speak Out"

31. "Mom's and Dad's in Wheelchairs Can Be Great Parents"

32. "Special Parents, Special Needs"

33. "Custody and The Disabled"

34. Parenting from a Wheelchair: Couple Prove it Can Be Done"

35. "The Disabled Parent"

36. "Handling and Infant Caring Techniques"

37. "An Approach to Motherhood for Disabled Women"

38. "Fighting for The Right To Raise Kids"

39. "How Brain Injury Affects Parents & Children"

40. "Mother-To-Be: A Guide To Pregnancy and Birth for Mothers With Disabilities"

41. "A New Alphabet for Parents"

42. "Products & Techniques That Enhance Parenting for Individuals With Spinal Cord Injuries"

43. "Having A Baby"

44. "Parenting With A Disability - Does It Make A Difference?"

45. "Spoiling Point"

46. "Day Care Laws"

47. "Adaptation for Parents With Disabilities"

48. "Single, Disabled, Parent"

49. "Rights of Disabled Parents"

50. "Childbearing Issues for Women With Physical Disabilities"

51. "Parents With Physical Disabilities and Their Babies"

Books, Videos - Magazines

1. I'm a Mom Now — Video
2. Jane's Day — Video
3. Parenting Accent Guide — Book
4. Spinal Network- "Family Matters "— Magazine
5. High Chairs and Children - Book
6. The Level of Door Knobs - Book
7. Step: The Parents Handbook - Book
8. A Guide to Parenting and Birth for Women with Disabilities - Book
9. Special Parents Special Children
10. Words in Our Hands
11. Help: When The Parent is Handicapped
12. Our Teacher's In a Wheelchair
13. Mama Zooms
14. In Silence - Growing Up Hearing In A Deaf World

15. Playing To Learn - Vudeo

16. Helping Kids To Behave - Video

17. Child Management - Video

18. So You're Going To Be A Parent - Video

19. The Art Of Communication - Video

20. Good Things For Babies - Book

21. The Child Wise Catalogue - Book

Newsletters

1. Resourceful Woman

2. ABLED Newsletter

3. Parenting With A Disability
   Through The Looking Glass

Growth and Development

1. ___ New born growth and development
2. ___ 2 month growth and development
3. ___ 0-3 month growth and development
4. ___ 3-6 month growth and development
5. ___ 4 month growth and development
6. ___ 6-12 month growth and development
7. ___ 7 month growth and development
8. ___ 10 month growth and development
9. ___ 12 month growth and development
10. ___ Infant behavior 0-12 month
11. ___ 1-2 years growth and development
12. ___ 15 month growth and development
13. ___ 18 month growth and development
14. ___ Toddler growth and development

15. ___ Toddler behavior 1-3 years

16. ___ 2-3 years growth and development

17. ___ 24 month growth and development

18. ___ 3-5 years growth and development

19. ___ Middle childhood growth and development

20. ___ Middle years behavior 6-12 years

21. ___ Adolescent growth and development 13+

22. ___ Growth and fine motor skills

Discipline

1. __ Positive discipline
2. __ Attempts Self Direction
3. __ Time out
4. __ Positive reinforcement
5. __ Praise
6. __ Listening
7. __ Problem solving
8. __ Extinction
9. __ Substitution
10. __ Consequence
11. __ Positive reinforcement summary
12. __ Tips for effective discipline
13. __ Who's in charge
14. __ Discipline or punishment
15. __ Prevention of misbehavior

16. __ Why children have difficulty

17. __ Vaccinate against the Terrible Two's

18. __ Positive Parenting

18. __ Oh no, Now what?

19. __ Cooperative behavior

Stress

1. Stress - various ideas, notes etc.

Educational Programs
From the Cooperative Extension Office

1.. Building Strong Families - Playing To Learn

2. Building Strong Families - Helping Kids To Behave

4. Building Strong Families - How Kids Develop

APPENDIX E

JANUARY 1993

PAM REPEATER

PARENTING WITH A DISABILITY

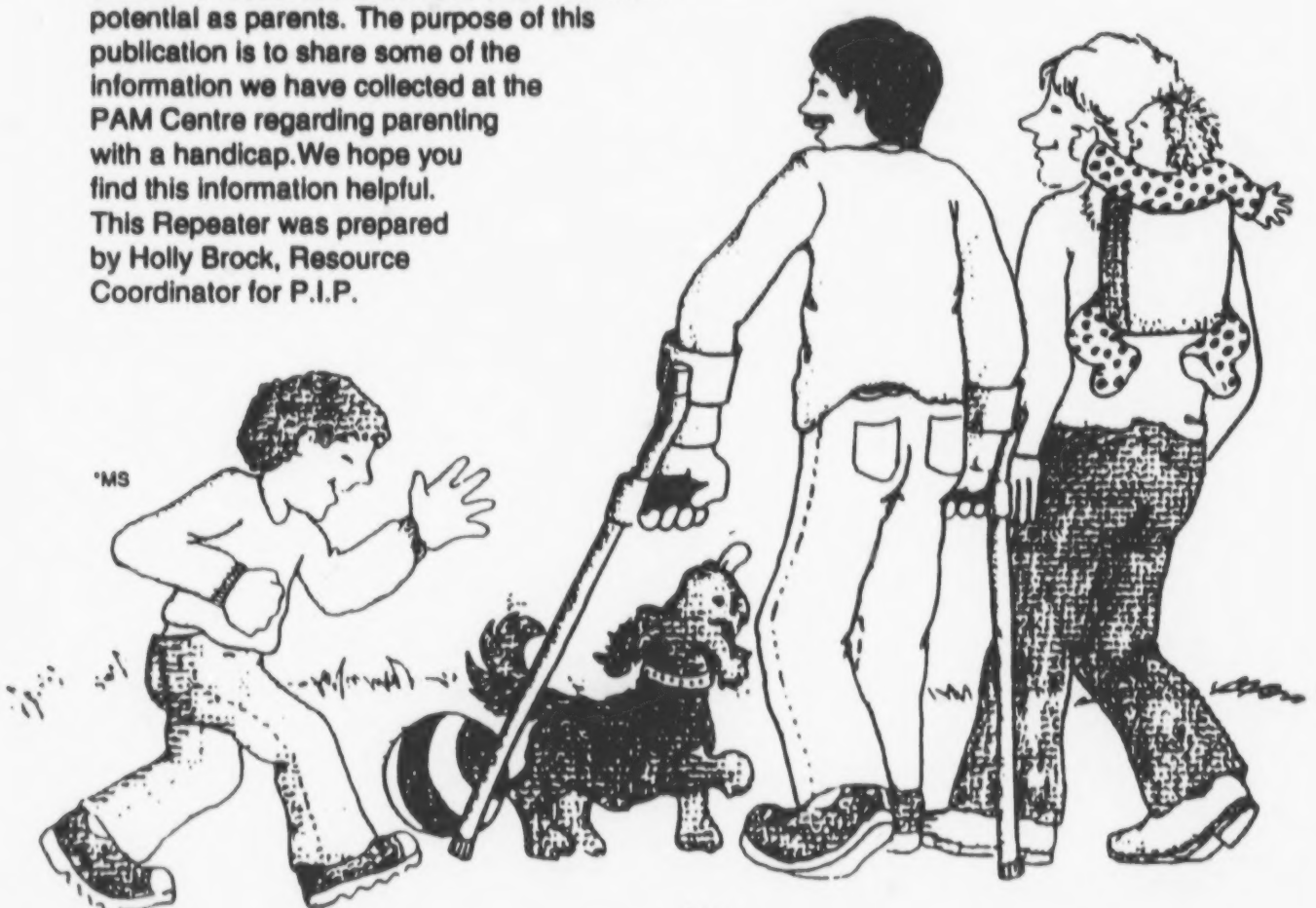
NO. 77

PUBLISHED AT:
PAM Assistance Centre
601 W. Maple Street
Lansing, MI 48906
(517) 371-5897 or
1-800-274-7426

Arselia Ensign, Editor

PARENTING WITH A DISABILITY

Adapting to the role of parenthood requires adjustment for all persons. However, adjusting to parenthood for some persons with physical disabilities requires additional accommodations. Changes in lifestyle, environmental adaptations and assistive technology may be necessary to make independent child care possible. Project Innovative Parenting (P.I.P.) was developed through a grant from Developmental Disabilities Council. The purpose of P.I.P. is to empower developmentally disabled persons with the appropriate skills and resources to achieve their maximum potential as parents. The purpose of this publication is to share some of the information we have collected at the PAM Centre regarding parenting with a handicap. We hope you find this information helpful. This Repeater was prepared by Holly Brock, Resource Coordinator for P.I.P.



COMPANY	1	2	3	4	5	6	7	8	9	10	11
PRODUCTS	★	★	★	★	★	★	★	★	★	★	★
Bottle/Pacifier Keeper						★	★				★
Sipper Gripper						★					★
Pacifier Case							★				★
Shoe Boppers							★				★
Snugli Bottle Warmer							★				
Lid Lock		★			★	★	★				★
Squeeze Feeder							★				
Sit 'N Secure					★		★				
Heart Beat Carrier				★		★	★				★
Sit Up Bottle Inserts							★				
Pacifier Plus					★		★				★
Safety Temp Dot Bottle	★										★
Velcro Diaper					★		★				★
Bath Pal Safety Thermometer						★					★
Swivel Bath Seat					★	★	★				★
Safety Kit						★					★
Tot Safe Harness						★	★				
Baby Bumpers Knee Pads					★	★	★				
Microwave Warm N' Serve					★						
Stove Knob Cover						★	★				★
Safety Changer					★		★	★			
Kid I.D.			★			★					★
Jar Holder 'N Spoon											★
Bottle Temp											★
Bathtub Safety Mat										★	

COMPANY	1	2	3	4	5	6	7	8	9	10	11
PRODUCTS	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Auto Bottle Warmer					✓	✓	✓		✓		
Kiddie Kart						✓					
Strok's Cradle Carrier		✓					✓				
The Tumbler		✓			✓	✓	✓				
Mini Sentry Alarm								✓			
Mobile							✓				
Safenet					✓	✓	✓				✓

COMPANY REFERENCE LIST

1 American Baby Concepts
P O Box 217
Wheatland, IA 52777

2 Hand In Hand
Catalog Center
Route 26
R R 1 Box 1425
Oxford, ME 04270-9745
1-800-872-9745

3 Kid I.D.
909 Marina Village Parkway #232
Alameda, CA 94501
415-523-4309

4 Leachco
P O Box 717
Ada, OK 74820
1-800-525-1050

5 One Step Ahead
P O Box 517
Lake Bluff, IL 60044
1-800-274-8440

6 Perfectly Safe
7245 Whipple Avenue NW
North Canton, OH 44720-7198
1-800-837-5437

7 The Right Start Catalog
Right Start Plaza
5334 Sterling Center Drive
Westlake Village, CA 91361
1-800-548-8531

8 Self Care Catalog
5850 Shellmound Street
Emeryville, CA 94662-0813
1-800-345-3371

9 Sensational Beginnings
P O Box 2009
300 Detroit Suite E
Monroe, MI 48161
1-800-444-2147

10 Underfoot
629 Maple Avenue
Bakersville, NC 28705
1-800-248-8999

11 Larger Department Stores
(Penney's, Sears, Toys r Us, etc.)

The following products can be found at the PAM Assistance Centre. They are examples of how technology might assist an individual with a disability to fulfill his/her responsibilities as a parent.

Bottle/Pacifier Keeper

If your child delights in tossing the bottle or pacifier and fetching is difficult for you, try securing it with this type of product. Attach one end to the stroller, crib etc., and the other end to bottle, toy or pacifier and it can be more easily retrieved.

Sipper Gripper

Sipper Gripper slides over a standard size juice box, and grip ribs hold it securely in place. Toddlers can use it as a training cup, and infants can use it too when a standard nipple is inserted. Two easy-grip handles are just right for small hands, and the plastic cap allows you to save leftover juice and use it on the go.

Pacifier Case

Strong plastic case protects a pacifier from germs when not in use. Dishwasher safe. Rinsing a dirty pacifier can be inconvenient, so this case may come in handy. Suggested adaptation: Attach a small piece of Velcro to the case and also to a handy spot on a highchair, stroller or wheelchair for easy reach and storage.

Shoe Boppers

To easily keep your child's shoelaces tied all day, simply slip on Shoe Boppers. Thread laces through, push a button, tug the laces and they'll stay fastened all day. Choose from hearts, bears, footballs or airplanes. For some parents, tying shoelaces may be painful or very difficult physically so this simple addition may be very helpful.

Snugli Bottle Warmer

This product could be very helpful when a bottle needs warming and you do not have a way to do so. Simply wrap the bottle with this liquid blanket, squeeze the metal disc and the liquid crystallizes and becomes hot. In just a few minutes the bottle is warm for baby. The Snugli can be recharged and ready to use again by heating in the microwave or boiling in water until all crystals have dissolved.

Lid Lock

Lid Lok keeps the toilet lid down, yet is easy for adults and toilet-trained children to use. Installs easily without tools. Helps avoid slammed fingers, accidental drownings and poisonings, not to mention sloppy messes.

Squeeze Feeder

If handling a baby food jar and spoon is difficult for you, perhaps the Squeeze Feeder can help. Place food inside and then neatly squeeze food onto the attached spoon. The self contained feeder is great if you are on the go, and cleans easily with a bottle brush.

Sit 'N Secure

Repeatedly repositioning or returning a child to his/her seat can be difficult for some parents. Cloth Sit 'N Secure straps children securely and comfortably in place in most straight back chairs so they can't wiggle and squirm out.

Heart Beat Carrier

For easier "loading" and "unloading", this baby carrier allows you to wrap and unwrap baby while he/she is lying down. The carrier distributes baby's weight evenly over parent's shoulders and baby can ride facing front or back. Velcro hitches and plastic buckles keep everything safe and easy to use. For children up to 30 pounds.

Sit Up Bottle Inserts

Insert fits inside a baby bottle and works like a straw in almost any upright position. Baby gets the liquid at the bottom, rather than air that stays on the top. Promotes good posture, lessens muscle strain and reduces colic. Also helpful if positioning a bottle is a concern.

Pacifier Plus

A heat-sensitive indicator located in the center of this pacifier nipple indicates if baby has a fever. When indicator stays green, temperature is normal. However, if the dot darkens and turns black, baby may have a fever and should be checked with a regular thermometer. Helpful if hands have decreased temperature sensitivity.

Safety Temp Dot Bottle

This bottle has an unusual tubular shape (looks a bit like a donut) with a canted neck. It is easy for baby to hold and helps prevent colic. The temp dot monitors the formula's temperature and lets you know if it is safe to drink. Green means safe, black is too hot. Can be heated in the microwave. Useful if temperature sensitivity is a problem.

Velcro Diaper

Disposable diapers are costly. And if you just can't manage diaper pins . . . try a Velcro cloth diaper. This diaper is made of 100% cotton flannel, is durable yet soft, machine washable and closes with Velcro. Outer and inner layers wrap baby in soft flannel. In between lies a leak proof plastic liner. For infants (newborn up to 24 pounds) and toddlers (24 - 45 pounds).

Bath Buddy Duck

This floating duck makes bathtime fun and safe because he is also a water thermometer. Sometimes nerve damage in fingers can make testing bath water temperature a real chore. This underwater thermometer accurately measures temperature with an easy-to-read display.

Swivel Bath Seat

This sturdy, safe, non-toxic plastic seat can make bath time easier if it is difficult for you to move all around the tub or if dexterity is compromised. The comfortable seat fits securely in any tub by suction. Once placed in the seat, baby can swivel 360 degrees and seat can be locked in any quarter turn position. For kids up to 25 pounds.

Safety Kit

Kit includes items to increase safety for baby in your home. Kit contains such items as plug locks, cabinet locks, drawer and cabinet latches and more.

Tot Safe Harness

Keep your child within three feet of you at all times. Tot Safe wraps around a youngster's chest with comfortable wide Velcro closing straps that won't restrict movement. It adjusts to fit many sizes and is machine washable. The 27 inch strap loops around parent's wrist or could be attached to a wheelchair or walker.

Baby Bumper Knee Pads

Thickly cushioned knee pads for babies 6 to 24 months old. With Velcro closures, the Bumpers protect baby's knees, tights and clothing. If a parent is a chair user, often it is easier to move around on wooden floors or floors covered with thin carpet. This can be rough on knees.

Warm and Serve Dish

This microwave safe dish has three sections, a removable cover, and a comfortable handle for easy use. Because it is covered, you can safely set down the dish, reducing the risk of spilling, and baby won't be able to dip fingers into the food. Its design makes putting food on the spoon easy. Dishwasher safe.

Stove Knob Cover

Clear washable plastic covers fit firmly over stove knobs so children cannot turn the knobs. Parents can install and use easily. Stoves that are accessible for chair users have knobs mounted on the front which can be inviting to little ones.

Safety Changer

Changing baby on a flat surface can be dangerous. The safety changer's gently angled sides cradle baby in a safe place. The vinyl covered fiberfill pad can be wiped clean with a damp cloth, weighs less than 3 pounds, and is portable. This product can turn a kitchen table into a changing table. A chair user can then roll closely to baby, eliminating the need for an adapted changing table.

Kid I.D.

This comfortable, adjustable, Velcro-closed elastic wristband has a concealed I.D. label with room for name, address and phone number. Ideal for traveling, shopping or any crowded, unfamiliar place. Can be worn again and again. Available in a variety of fun designs that kids will love.

Jar Holder 'N Spoon

This baby food jar holder allows you to hold two jars of food with one hand. Easy-to-hold handle also provides a place to hold a spoon (one included). All are microwave and dishwasher safe.

Bottle Temp

In 15 to 20 seconds, this highly sensitive temperature gauge lets you know when a bottle is the right temperature for feeding. Adjustable Velcro strap fits all size bottles. Microwavable. Ideal for those who have difficulty sensing temperature.

These products are available to consumers and may also be beneficial.

Safety Bathmat

The Thermo mat tub and shower safety mat has a color coded temperature gauge on it that lets you know if water is a safe temperature. The mat is exceptionally slip-resistant and comes in a variety of designs, including exciting ones the kids will like. Nerve damage in fingers and hands may make it difficult to accurately test water temperature. This mat can assist in making that judgment.

Auto Bottle Warmer

Easily warm a bottle on the road by plugging this warmer into the car's cigarette lighter. The warmer wraps securely around a bottle and warms it in minutes. Small enough to store in diaper bag or glove compartment.

Kiddie Kart

This tough no-tip trailer ordinarily attaches to the back of a bicycle for transporting little ones safely. This product could be adapted to attach to the back of a wheelchair. Seatbelts hold children securely. Depending on the model, child either rides facing forward or backward.

Stork's Cradle Carrier

This baby carrier safely cradles baby close to Mom or Dad in a thick washable pad that straps on comfortably. The design distributes baby's weight and secures with Velcro. If a parent has a difficult time holding baby closely, especially for nursing, the carrier might be useful.

The Tumbler

This durable and dishwasher safe cup is completely spillproof. When dropped, tipped upside down or left on its side, liquid stays inside the cup. Great if cleaning spills is difficult.

Mini Sentry Alarm

This small alarm senses motion anywhere you place it in an area 32 feet forward and an 85 degree angle. Placed near a child's room or by a door leading outside, a siren or soft chimes (you choose the sound) sounds when it detects motion. Requires three AA batteries. Could be very useful for visually impaired or mobility impaired parents.

3 In 1 Mobile

Noise from baby activates this mobile. It gently lights up, spins around and plays music, twirling plush bears, balls and blocks. Turns off automatically or manually. Can be programmed.

Safenet

Plastic mesh safenet keeps children on the safe side of decks, porches, stairways and balconies by fitting across railings with wide spaces. It is easy to install, washable, and can stand up to outdoor weather.

PARENTING, an Accent Guide, is a compilation of articles written by parents who have a disability. They offer tips on raising children based on personal experience. Following are samples of their suggestions.

• "When Both Parents Are Disabled" by Bonnie Bonham

Bonnie and husband George are both post-polio survivors. George walked with kinney sticks and Bonnie, although able to walk unassisted, could not carry anything of substantial weight since balance was delicate. Once Baby arrived, they had to find creative solutions to compensate for this. They added heavy weight round casters to a port-a-crib so they could easily and safely roll it around their home. Small enough to move from room to room, the port-a-crib became their "arms" for transporting their children. The side came down, so, while seated, the children could easily be taken in and out of the crib. This was the answer for them for travel "in house." However, they needed a different system for transportation outside the home. For their first child, a high quality stroller was used that could be disassembled and lifted into the trunk easily. For the second child, a simple umbrella type stroller made transporting easier.

As parents, issues of great importance in raising children were training and trust. They feel strongly that you must train children as to what is right, then trust that they will remember and act accordingly once out in the world. It was difficult to trust toddlers not to run where they could not be caught; to trust that they would not run into the street, run away while shopping, or dart away when getting in and out of the car. They taught them (with occasional spankings), but mainly always talked with them so they would feel and understand how important certain requirements were.

• "Helpful Hints For Handling Three Children," by Margaret Timmerman

Contracting polio in her late teens meant wearing a long leg brace, a back brace and walking with crutches for Margaret. Poor balance meant the need for creativity for transporting Baby. A regular crib and a portable crib were used since it was unsafe to carry Baby. For the new baby, husband George built a baby bed to sit on top of Margaret's walker, enabling her to travel from room to room with minimum effort. One side of the bed opened out, which allowed her to remove Baby while seated. The walker seat held extra diapers for changing time. Baby was never left alone on the walker bed.

The solution for taking Baby out was the purchase of a stroller that converted into a bed. After checking her balance, Mom lifted Baby from the crib to the walker bed, then rolled out to the car. After getting seated in the driver's seat, she lifted Baby into the car bed beside her. At their destination, the stroller bed was retrieved from the trunk and the procedure was reversed. One hand pushed the stroller and the other manipulated a crutch.

Margaret feels it is essential to be organized; have what you need within reach. Cleaning supplies and hazardous materials should be up high, out of Baby's reach. Pots and pans and canned goods can be placed on lower shelves, giving the creeper something to play with.

When lifting is a problem, raising a playpen about 18 inches from the floor makes it much more manageable. With a door on one side, Baby can be changed in the playpen and taken in and out more easily.

When Baby starts to creep (at about 40 weeks) there are some safety measures to take to ensure Baby's safety and Mom's sanity. Margaret placed Baby in a walker and put gates in doorways to keep mother and child in the same room. Putting things up and out of reach helped Mom stop the child when she said "no".

• "Sleeping At Night" by Kaye Harding

Because Kaye had to walk with leg braces and crutches, carrying anything was out of the question. To manage day care, Mother used a lightweight carriage for indoor transportation of Baby and various items necessary for sleeping, feeding and diaper changing. Her husband was very helpful in taking the night shift. Since their baby did not fit the typical infant pattern of eating and sleeping, the parents were forced to take desperate measures (like propping Baby on the dining room table in front of the TV), but to no avail.

From reading Dr. Spock's book Baby and Child Care, it seemed that rocking was acceptable if all apparent needs were taken care of, but Baby was still fussy. Creativity gave birth to a rocking crib. Crib wheels were removed and replaced with a spring assembly. Tying a cord to one post of the crib and the other to Dad's wrist or big toe enabled him to give a little tug to the cord and the crib would gently rock.

This effectively calmed a fussing child. Shortly, Baby became accustomed to this motion and moved into a crouching position. Slight movement enabled Baby to start this motion by herself.

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• "Can A Woman Who Uses A Wheelchair Have A Baby?" by Jean Moore

Jean became a wheelchair user due to polio. When deciding to have a baby, she knew it was essential to preplan and prepare in advance for pregnancy, childbirth and child care. She consulted her physician about her health and special needs. She visited the maternity ward to investigate rooms, doorways, bathroom facilities and alternatives. Discussions with the hospital staff were important in preparation for the birth. It was essential to plan for transportation in advance. She found childbirth classes most helpful.

She suggested that equipment (crib, stroller etc.) be very sturdy, since you may lean on it more than most people. Baby paraphernalia should be arranged for your convenience. A steel tray across her wheelchair was most helpful to Kaye. It was secured to the chair by a bolt and butterfly nut through a hole in one arm of the chair. A plastic foam pad was enclosed with waterproof plastic, slip-covered and held to the tray with a strong band of split diapers. This band was also used to secure Baby so he could not turn or fall off. The padded tray was used for diapering, bathing, feeding, playing and for transporting Baby from place to place.

When able to sit up by himself, Baby rode around on Mom's lap, secured by a band around the chair, Mom and Baby. This freed mom's arms for wheeling. Bathing took place in the kitchen sink.

As mobility developed, a halter (the type used for stroller and highchair safety) made it possible for Kaye to lift Baby from the floor. Once walking, a rope was attached to the halter and to an eye screw just outside the door, allowing the child to enjoy the fresh air outdoors.

Combining activities reduced stress and danger, and saved energy. She entertained Baby while ironing by propping a storybook on the ironing board. She peeled vegetables on the wheelchair tray and cooked while Baby soaked and splashed in the kitchen sink. Small jobs such as sweeping with a hand broom and dust pan or washing play dishes kept little ones busy and feeling helpful while Kaye tended to necessary household tasks.

Diane Dawson-Ryan is one of PIP's parent mentors. We asked Diane if she would share with us some ideas and helpful hints that she found to be especially useful in her experiences raising her daughter. Following are her ideas and suggestions:

* back pack as a diaper bag
* camera case as a small diaper bag - holds one change
* empty film container will hold a small plastic bag for dirty diapers or clothes
* portacrib mattress or several towels on the floor for a quick changing area
* knee socks - slip over hands and arms before putting on snowsuit, can be used as mittens and prevents the gap between sleeve and mitten
* bar of soap - stick diaper pins in it to hold them and the soap makes them easier to pierce diapers
* plant hanger - suspend near changing area to hold "extras" i.e., toys
* gate hooks with spring latches for cabinets and doors
* cotton and masking tape - cover corners of end tables to soften sharp edges
* fanny pack - in a pinch, use as a safety strap in a highchair or swing
* put tape over bathroom door locks to disable them
* attach a rope to banister supports - it will hang below banister for child to grab for support
* diaper stacker - hang from to hold underwear, shirts etc. within child's reach
* kitchen trash can with foot pedal - line with kitchen size trash bags to make diaper pail with liner
* barrettes will hold overalls straps together and prevent them from slipping off shoulders
* terry cloth pony tail loops fit over wrists while eating juicy fruit (oranges etc.) so juice will not run down arms (and they are washable)
* vinyl sheeting (available in fabric stores in clear or designs) great under high chair and car seat -also works well in play area for play dough type clay
* pillows can serve as bed rails in a pinch - slide under fitted sheet on both sides of bed
* changing table - slip in closet as an extra dresser or use to hold toys for older child
* small bookcase can be used to hold young child's clothes and they can be easily picked out
* multi drawer nut and bolt type case keeps crayons and small toys off the floor and out of the way
* baby wipe boxes hold lots of small things, doll clothes, cars, blocks, cards - label and stack
* elastic pony tail loops - slip through zipper hole to make it easier for toddler to grasp
* survival blanket - put under toddler's sheet to give extra warmth in winter
* fitted cradle or portacrib sheet can be fitted over car seat when not in use - protects from the sun
* teething rings - keep chilled in refrigerator to put on bumps and scrapes

* teething gel - apply to skin before removing sliver, to numb a bite
* baby gate - when no longer needed as a gate, use as a hanger for damp towels
* ice cream - let child eat this or other cold item before and after taking medicine (to numb the tongue)
* elastic shoe strings - to assist with putting on shoes
* nail brush in laundry area can be used to scrub set in stains

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Diane also found these products most helpful:

* snap or Velcro strap booties (non-slip soles for toddlers)
* glow in the dark pacifiers
* pacifier with temperature sensor
* Velcro strap shoes
* sound activated mobile
* temperature sensor bottles or clips
* snap, Velcro or slipover cotton bibs (machine washable)
* infant monitor
* pacifier keeper - keeps pacifier, small toys, rattle etc. attached to baby, car seat cover, baby carrier
* baby carrier, both front and back styles
* stain stick (etc.) keep next to sink, changing area, laundry room
* shopping cart seat - a variety of styles
* bib clips (Playskool) - very good purse item
* sun shade for car
* car seat toy - attach to car seat
* snowsuit - the kind that grows with baby so it can be used 2 to 3 winters
* stroller cover - plastic covering to protect child from the elements
* car seat covers make the seat more comfortable
* Cheerio holder (by General Mills) looks like a large Cheerio and holds one cup of cereal
* disposable sipper cups and/or lids - a variety of bottle companies sell these to turn bottle into sipper bottle
* sit 'n sip bottle straw
* wrist leash security cords - when child learns to unfasten Velcro, fasten on back belt loop of trousers or through back strap of jumpsuit
* harness, with or without leash - variety of styles
* high chair/booster seat combination, can grow with child
* child proof kit and infant/child safety and first aid book
* suction bowl with lip - helps with self feeding
* thermometer strips - much easier for taking temperature
* stroller - get the biggest wheels you can find
* stroller bumper guard, fits most umbrella strollers and helps keep child seated (LUV Buggy stroller accessories)
* door alarm (Safe T Guard) alarms when door is opened
* hands off alarm (Safe T Guard) is light activated, alarms when cabinet or drawer is opened
* sliding lock for medicine cabinet door
* tot minder (Safe T Guard) or Nany (Welsh Co.) attach to child, alarm if child gets out of preset range child can activate if frightened
* safety mat - alarms when stepped on - can be placed in front of door (Nash Industries)
* motion alarm - when hung over a door, will sound an alarm when door is moved (battery operated)
* faucet cover for bathtub
* floating thermometer for bathtub
* large crayons for toddlers
* child I.D. kit

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OTHER PARENTING RESOURCES

Adapted Furniture

"The Disabled Parent," p. 162, The Source Book for the Disabled, Imprint Books, London, 1979.

Mary Free Bed Rehabilitation Center, 235 Wealthy St. SE, Grand Rapids, MI 49503. The Technical Equipment Program displays and will adapt baby furniture. They can adapt the following: crib, playpen, padded rolling cart, changing table, and custom baby lap tray.

Respite

· Lansing Area Parents (LAP) Respite Center, 840 E. Mt. Hope, Suite 206, Lansing, MI 48910, (517) 334-2887. This is a family-directed program providing respite care, information and other supportive services for families caring for children who are handicapped or chronically ill. Respite care relieves family caregivers by contracting through LAP to do caregiving. Arranged by prior agreement or on an emergency basis, registered families can receive a few hours or a few days of respite care. Services are in-home, center-based, or on a co-op family basis. LAP Respite Center also offers information-services, family support services, family advocacy services and volunteer services. Inquiries and applications can be made at the LAP Respite Center. Fees for services are based on a sliding scale and ability to pay. TDD: 1-800-649-3777.

Family Growth Center, (517) 484-2610

From three locations in the Lansing area, the Family Growth Center offers several programs for families to enjoy. For children: free drop in child care, kindergarten readiness programs, fun and age-appropriate activities. For parents: free workshops (positive discipline, communication skills with their child, building self-esteem, stepfamily issues, stress management), weekly support groups, and information and referral services. Families can find a parent nurturing program, seasonal parties and programs to strengthen family relationships.

MB

Editor's note:
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P.I.P.

PROJECT INNOVATIVE PARENTING

If the answer is **YES** to these questions, maybe P.I.P. can help!

Do you have a physical disability that you have had since you were young?

Do you look after a child who is 6 years old or younger?

As a parent with a handicap, do you have trouble doing things you need to do?

Do you have questions about having children?

P.I.P. helps parents who have disabilities learn:

* normal infant and child development
* parent/child bonding
* physical management of young children
* discipline
* selection of appropriate toys
* finding special equipment for child care

For more information about P.I.P., contact:

Project Innovative Parenting
PAM Assistance Centre
601 W. Maple
Lansing, MI 48906
517-371-5897 or
1-800-274-7426
Voice or TDD

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WHAT DOES THE PAM CENTRE DO?

The PAM ASSISTANCE CENTRE provides information about assistive devices-- what they are, what they cost and how they can be purchased. Innovative and practical suggestions are sought for our PAM clients.

HOW DOES THE CENTRE HELP? WHO IS ELIGIBLE?

Centre staff specializes in problem-solving, working with medical personnel, special educators, parents and directly with any persons for who special equipment may be of benefit. ***Note:*** *Any person with a disability is eligible for our help without cost or "red tape".*

WHAT POPULATION IS SERVED?

All ages are eligible for service. The special education population (ages 0-25), rehabilitation clients, and older persons are included. Persons with physical, mental or multiple disabilities or disabilities of sight or hearing will find the Centre helpful.

IF NOTHING IS ACTUALLY SOLD, WHAT DO YOU DO?

The Centre offers information from more than three thousand companies, concerning more than thirty thousand products. When the occasion calls for it, ABLEDATA (a national database) is available to supplement the Centre's abundant resources. Sometime a homemade device or the innovative use of some standard item is suggested.

HOW FAR DO CENTRE SERVICES EXTEND GEOGRAPHICALLY?

PAM is a service for Michigan, although out-of-state requests are also honored. A majority of requests for problem-solving are initiated by phone. Often the calls come from persons who have visited the PAM Centre and personally acquainted themselves with the Centre staff and resources.

WHAT IS THE BEST WAY FOR US TO USE PAM SERVICES FOR SOLVING AN INDIVIDUAL PROBLEM?

Most questions can be answered and problems solved by phone and/or mail. In other instances, it is highly desirable to establish face-to-face contact with the person who has the particular limitation or the parent involved. This can be accomplished by a visit to the Centre in Lansing. Whenever possible, we ask that you arrange in advance for an appointment.

HOW DO I GET ON YOUR MAILING LIST?

Our membership/subscription fee is $10 per year, on a calendar year basis. Make your check payable to P.I.A.M. and mail or bring it to the Centre. ($25 organizations).

IF MY NEEDS ARE 'HIGH-TECH', PERHAPS INVOLVING COMPUTERS, WHAT DO I DO?

No problem! *Contact our "sister" center, the Living and Learning Resource Centre, located on the campus of the Michigan School for the Blind. Phone: 517-487-0883 (Voice or TDD) or MI toll-free 800-833-1996.*

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PAM Assistance Centre
601 W. Maple Street
Lansing, MI 48906
517-371-5897
800-274-7426
Voice or TDD

Note: Information from PAM and LLRC is generally classified in these categories.

APPENDIX F

Project Evaluation
as reported by
Parents Involved
with PIP

Indicate your response by entering a number from the following scale after each question.

1- Significantly
2- Moderately
3- Some
4- A little
5- Not at all

	1	2	3	4	5
1. Overall, has involvement with PIP reduced the stress in your family life?	☐	☐	☐	☐	☐
2. Has involvement with PIP made your role as a parent easier or better?	☐	☐	☐	☐	☐
3. Has the PIP program increased your knowledge about resources or community services, how to find and how to access needed services?	☐	☐	☐	☐	☐
4. Does the help you receive through PIP enhance your parenting skills?	☐	☐	☐	☐	☐
5. How satisfied are you with your communication with the staff of PIP? How could it be improved?	☐	☐	☐	☐	☐
6. Are you receiving information or assistance that is clear and useful to yourselves as parents?	☐	☐	☐	☐	☐
7. Are you receiving information in a timely manner?	☐	☐	☐	☐	☐

Comments on questions 3,4,5,6

3.

4.

5.

6.

8. What has been the greatest benefit of PIP involvement in regard to parenting?

9. What changes would you like to see in PIP?

10. What role would you like for mentors to play? Mentors are persons who can share similar life experiences in a helpful manner. For example, other handicapper parents.

Demographic:

11. How did you first hear about PIP?

____ Brochures ____ Friend ____ TV
____ Agency ____ School ___ Meeting
____ Doctor ____ Other

12 . How long have you been involved in PIP:

____ 0-4 months
____ 5-9 months
____ 10-14 months
____ 14-18 months
____ Over 19 months

13. Is the amount of involvement with PIP:

____ More than enough
____ Just enough
____ Not quite enough
____ Not enough

14. Who fulfills the parenting role for your child or children?

_____ self ____male____female
_____ spouse _____male_____female
_____ both parents
_____ other (please describe)

15. Indicate your race: (Optional)

_____ Asian
_____ African-American
_____ Caucasian
_____ Hispanic
_____ Native American
_____ Other

16. Check the age category of the adult caregivers of the children in your family.

____ 18-20 ____ 21-25 ____ 26-30 ____ 31-40
____ 41-50 ____ 51-60 ____ 61-70 ____Over 70

17. Please check the age categories of your children. Check all as appropriate.

___0-2yr. ___3yr.-5yr. ___6yr.-8yr. ___over 9 yrs.

18. Check your approximate yearly income category.

_____ below $6,000
_____ 6,000 -12,000
_____ 12,001-16,000
_____ 16,001-20,000
_____ 20,001-25,000
_____ 25,001-30,000
_____ Over 30,000

Other comments about Project Innovative Parenting:

Thank you for taking the time to fill out this evaluation of PIP. We feel that this information will be helpful to us as we endeavor to become even more helful to you.